



# Mal de Debarquement Support News

A Newsletter for the International Members of the MdDS Support Group and the Professionals Who Treat Them

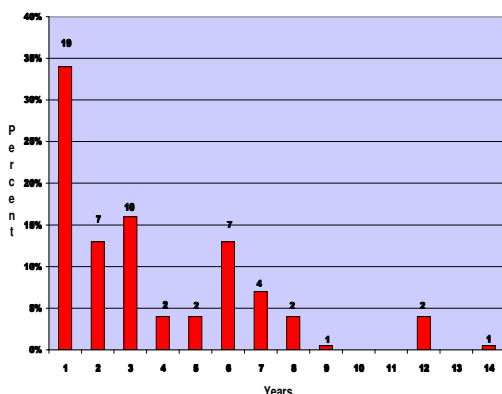
Volume 18

July, 2007

## Duration of Symptoms

Seventy- seven people responded to an online survey aimed at gathering current information about the duration of MdDS symptoms. This survey was posted June 16-30. Of the 77 subjects, 57 are experiencing their first and only episode with Mal de Debarquement. The mean duration of symptoms for this group is 4 years with a standard deviation of 3.3 years, and the standard error of the mean being, 0.45. The longest single episode reported was 14 years.

Duration of Symptoms



Two of the responding subjects are currently in remission. One had a two year, six month episode while the other has experienced six episodes that range from 3 to 6 months.

Eighteen subjects who are currently symptomatic have experienced multiple episodes ranging from 1 month to 9 years, 8 months.

Full size graph available on page 2.

\*Participation in these surveys is strictly voluntary.

My first episode followed a paddle wheeler ride down the gentle Mississippi River. JL

## The Boat Never Left the Dock, But I Still Rock

In January 1988 I worked at an office selling special events/catering for a 110' yacht. I only had to go on the boat while docked to show it to potential customers. On the third day I started rocking. Everyone said I would get my sea legs in a few days. It was so bad my doctor referred me to an ENT. I had physical therapy three times a week for six weeks. One of the medicines I was prescribed was Antivert. I quit my job and three days later the rocking stopped. This was the most horrible experience I had ever been through! I became a Christian during this time, and give all credit to God!

My next episode began two days after I flew home from a site inspection I conducted in August 1999, which included a ferryboat ride on the Chattanooga River. That episode lasted about four months. I didn't bother seeing a doctor - I knew nothing would help.

My third episode began August 2005 while in New York for a wedding. My family opted for a sailboat ride with the bride's parents, which I declined. My cousin arrived on his motorcycle an hour later and I had the most incredible four-hour tour of Niagara Falls from the Canadian side! The day after I flew home I woke up with my worst episode.

I saw an MD, ENT, and a chiropractor. In October, 2005 a friend referred me to an audiologist who tested me for more than two hours FREE - she diagnosed me on the spot.

I found the MdDS website through a link on United Health Care's site. I finally saw a neurologist in January 2006 and asked him to prescribe clonazepam. I stopped it after a week, as it left me so drowsy I couldn't function. By the end of May I was so bad I decided to try it again, encouraged from reading of others' success with it on the support site. This time I took only .05mg at about 10 p.m. - I was asleep in 10 minutes.

My symptoms went from a 10 to about three within two days. I discovered I was being laid off three days later, so I was very grateful to find a means to manage the MdDS. I don't take another dose in the afternoon. Today, I am almost symptom free daily until about 7 p.m. when some slight rocking occurs. I doubt I'm hardly ever above what I describe as a "2" compared to my old symptoms. I never had headaches, nausea, sinus problems or many of the other things discussed on the support site.

I find lack of activity will start up some symptoms: for example, on days when I have been on the computer for hours without much activity. Sitting still for long periods will bring on some rocking and my head feels heavy. My greatest problems are late afternoon fatigue and dyslexia in my writing and speaking - my brain is going faster than I can type or speak. Sometimes I think people must think I am slurring my words.

I was laid off AGAIN April 13 and have had no luck finding employment. I KNOW for a fact stress is my one trigger, so I am leaving everything in God's hands. I am volunteering to stay busy and keep my computer skills fresh.

## PUBLICITY NEWS

June was an outstanding month for MdDS publicity. On June 12, 2007, **The New York Times** featured an article in its Tuesday Health Section by Elizabeth Svoboda entitled, "When Seasickness Persists After Return to Solid Ground." She relied on the expertise of a number of advisory council members. Marilyn Josselyn, co-founder of the MdDS Balance Disorder Foundation, described her life changing experiences with MdDS.

Jane H. was interviewed by a local news show on **Channel 5** in England. The UK's **Daily Mail** reporter, Barney Calman wrote an article featuring Rachel sharing her experiences with MdDS. The article was called, "Sea-sick all the time...and I've never been on a boat."

Renee shared an article that was published this spring in the **Curry Coastal Pilot**, a newspaper in Brookings, Oregon, entitled, "DOING A DAILY BALANCING ACT: LOCAL WOMAN FIGHTS RARE DISORDER." Written by Tom Hubka, it featured quotes from Dr. Timothy Hain.

Click on [www.mddsfoundation.org](http://www.mddsfoundation.org) for direct links to these media stories!

Support group membership has grown to 558.

Please send tax deductible contributions to:

MdDS Balance Disorder Foundation  
Marilyn or Roger Josselyn  
255 Copper Beech Drive,  
Blue Bell, PA 19422.

ICD-9 780.4, Indexed

If you are interested in volunteering to assist with our programs, please email:

Roger at [rjosselyn2@comcast.net](mailto:rjosselyn2@comcast.net) or

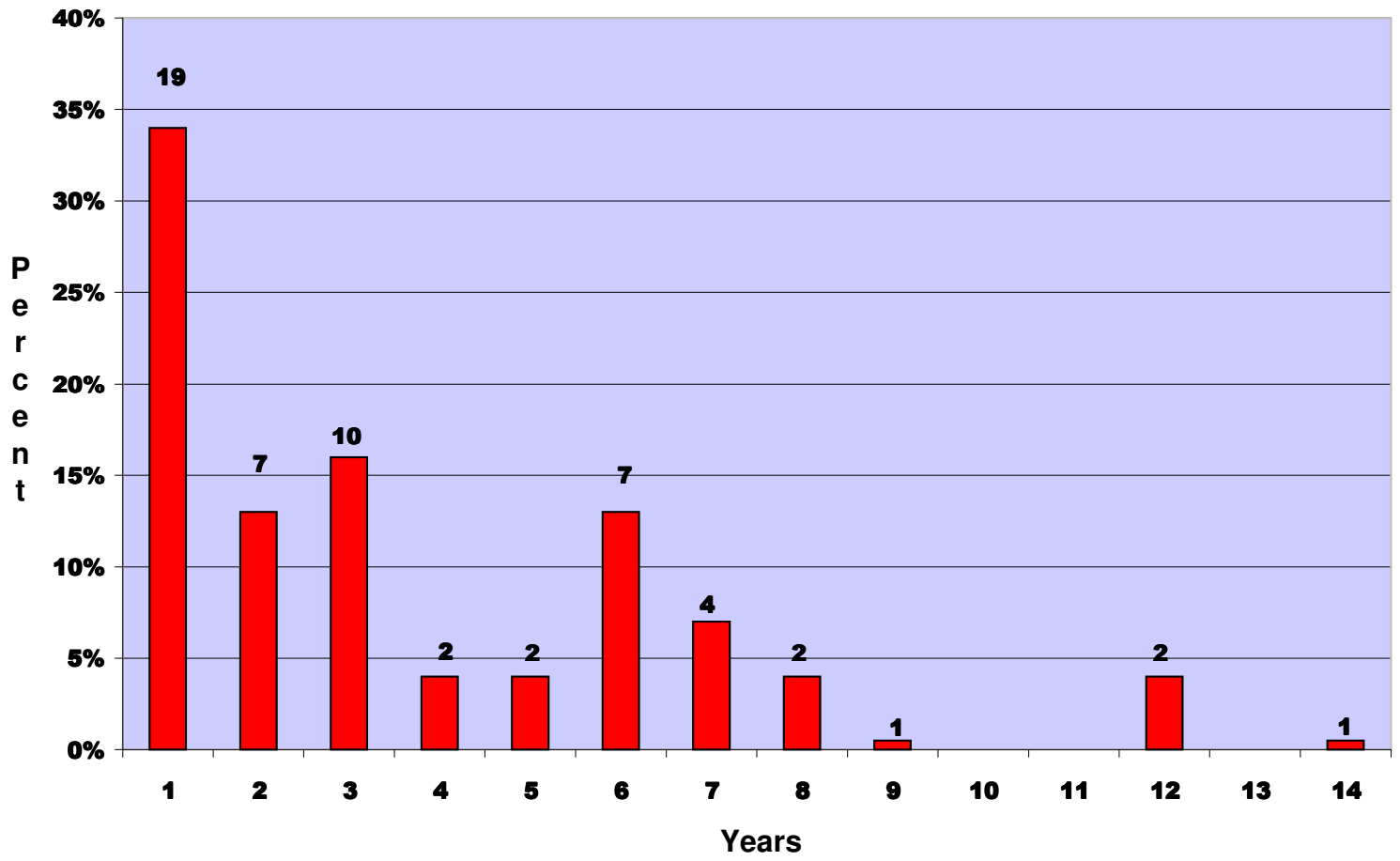
Marla at [mcrnor@msn.com](mailto:mcrnor@msn.com)

[mddsfoundation@yahoo.com](mailto:mddsfoundation@yahoo.com)

<http://mddsfoundation.org/>

Send comments, questions, or suggestions to the Newsletter Editor ([editor@mddsfoundation.org](mailto:editor@mddsfoundation.org))

## Duration of First Episode MdDS Symptoms



Mean= 4 years  
Standard Deviation= 3.3 years